



Ucare

The Caregiver Guide

Module 14

Caring for the Child with Special Health Care Needs

Participant Booklet

UCARE Module 14

Caring for the Child with Special Health Care Needs

PURPOSE



Module 14 will provide you with basic information for identifying supports and resources, interacting with professionals, organizing records, and planning for future events.

WHAT YOU WILL LEARN

After completing this module you will be able to:

- Identify various types of information to collect related to your child with special health care needs
- List informal and formal supports and ways to use effective advocacy strategies
- Identify techniques for developing parent and professional partnerships
- Identify ways to organize financial information and records
- Identify key components for planning for the future

Handouts are also enclosed in your packet these include:

- Local community resources
- State level resources
- Website and national level resources

PARENTS' STORY

Information and planning is essential to regaining control of your life and making informed decisions.

“The day my child was diagnosed as having a disability, I was devastated and so confused that I recall little else about those first days other than the heartbreak.”

Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways.

Another parent described the trauma as “having a knife stuck in her heart.”

Parents' feelings

At first you may go through the stages of grief that everyone experiences after a loss. These can include shock, disbelief, anger, blame, guilt, questioning of why it happened to you and your child, and panic or fear that you will not be able to cope.

These feelings can (but not necessarily) come back at different stages through your child's life as new losses happen such as your child not being able to participate in community activities or become fully independent. So while you can achieve healing, you may feel loss at other times.

Take time to grieve when you need to. You do not have to bear this burden alone; there is much help available to you.

Notes:

GATHERING INFORMATION

- Join a group
- Read books



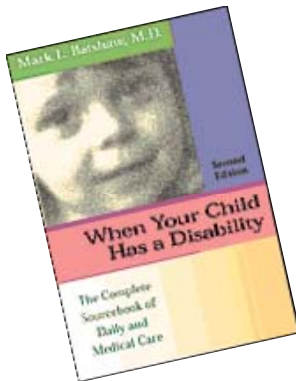
Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourselves. For this reason, it is useful to join a parent's group, which can offer you the opportunity to meet and talk with other parents and caregivers who have children with special needs.

Types of groups:

- Particular disability (e.g. Autism, Down syndrome),
- Similar concerns (e.g. daycare, transportation, stress management, or finding out community programs)

Find a group:

Your doctor, child's teacher, or the Utah Parent's Center may know of groups that meet in your town. Your packet has a list of some of the groups in the state.



Reading books:

Books written by parents of children with special needs provide information about what they have learned and experienced. They may provide you with information that will help you identify appropriate supports and services.

Notes:

INFORMATION AND PROGRAMS

- Seek information
- Find programs for your child

Seek information:

Don't be afraid to ask questions. Asking questions is one of the first steps in understanding more about your child and the special needs he or she has. Some parents want a lot of information all at once while others find that a little at a time allows them to put things into perspective.

**Get accurate
information**

The important thing is that you get accurate information. There is also a list of good parent support websites in your packet. The Internet can connect you with a lot of information. But, be careful believing all you read. Good and accurate information will be referenced to research or formal studies.

Find programs for your child:

Even if you live in the most rural county, assistance is available to help you with whatever information or supports you need. Contact your local school district or health department. Talk with you doctor or church leaders.



Ask Questions

There are programs for children and your family available within your city or town. Fun programs to get your child involved in community activities include:

Community services:

- 4-H
- scouting
- Programs at the local recreation center

Support programs include:

- Bishop's Storehouse (LDS church)
- Community Health Clinic
- Department of Workforce Services (job, food stamps, Medicaid, child care, heat assistance, telephone lifeline assistance)
- Community Food Pantry

Notes:

Two programs for intervention services available under the Individuals with Education Act are:

Education services:



- Early intervention services: Early intervention services are designed to address the needs of infants and toddlers with disabilities and their families as early as possible. www.utahbabywatch.org 1-800-961-4226
- Special education and related services: each eligible child with special health care needs is guaranteed a free, appropriate public education designed to address his or her unique needs. www.usoe.k12.ut.us

Remember:

While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

STAY POSITIVE

- Maintain a positive outlook
- Keep the lines of communication open

Focusing on the positives can help diminish the negatives.

Maintain a positive outlook:

Focusing on the positives can help diminish the negatives. For example, your child may have a profound hearing loss, but be a very healthy child. Take time to enjoy your family and the activities you share together. Take each day and problem at a time and keep daily routines as normal as possible.

Keep the lines of communication open:

The more you are able to communicate with your spouse, partner or supporting family members during the initial diagnosis and at other difficult times, the greater your combined strength. Remember that each person will approach their role as a parent differently. How you and your partner feel and respond to new challenges may not be the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

Notes:

EMOTIONS AND RELATIONSHIPS



- Don't be afraid to show emotion
- Make time for your own relationships
- Don't forget your other children
- Don't forget to ask for help

Don't be afraid to show emotion:

So many parents, especially dads, hold back their emotions because they believe it may be a sign of weakness to let people

know how they are feeling. It is healthy and normal to show emotions. Sometimes professional counseling is warranted; if you feel that this might help you; do not be reluctant to seek help.

In addition to dealing with emotions having a child with special health care needs will impact your personal and family relationships if you let it. Here are a few ways to maintain strong relationships.

Make time for your own relationships:

This may feel like you're cheating on your responsibilities. But it is important for your mental health and the health of those around you. Share time with your partner. Make a date night once a month. Spend time with other adults (talking and caring for children all day is tiring).



Don't forget your other children:

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family who can talk with them honestly about the things that are concerning them. Some siblings find having a brother or sister with a disability a positive experience and they are often more willing to accept people for who they are. Other siblings may feel fear, resentment, jealousy, and neglect. Make opportunities for your child to express how they feel.

Don't forget to ask for help:

Everyone needs breaks to rejuvenate and gain new perspectives. Make a list of friends, family, and neighbors who can provide different types of support. For instance, you may have a friend

that knows your child well and has offered to watch him; you may have a sister who enjoys shopping and could pick up your list of groceries.

Notes:

PARENT AND PROFESSIONAL RELATIONSHIPS

- Work together with the professionals involved with your child
- Learn terminology
- Learn all you can about your child's disability
- Find a good relationship
- Weigh professional recommendations

Remember that
first and
foremost you are
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your child

Work together with professionals involved with your child:

Remember that first and foremost you are the parent of your child. As a parent, you have first hand knowledge of your child's needs, and professionals have a specialized knowledge of your child's needs. The best parent professional relationships are characterized by shared respect, trust, and openness. It is a relationship where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child.

Learn the terminology:

When you are introduced to new terminology, you should not feel embarrassed to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation and ask

the person to explain the word. It's important to understand the term well enough so that you are able to provide information to your child's doctor, teacher, or therapist, if needed.



Learn all you can:

Ask questions. Don't be concerned that you are being difficult by asking questions. Write down what you've been told. The important thing is that you request and receive accurate information. A good strategy is to write down your questions before going to appointments or meetings, and to write down further questions as you think of them. Get written copies of all documentation, reports, or professional articles from physicians, teachers, and therapists.

Find a good relationship:

Find a doctor and other professionals with whom you and your child can work comfortably. Try asking other parents who have children with special needs. They may be able to suggest the name of a doctor, speech pathologist, job coach or dentist.

Be honest with
what you can
realistically do
and what you
can't

Weigh professional recommendations:

Balance recommendations for services, therapy, and other treatments with your daily demands. Don't be intimidated by professionals who expect you to do it all. Be honest with what can realistically be done and what can't.

Notes:

RECORD KEEPING

Keep Accurate Records

- Health and medical records
- School records
- Financial

Keep accurate records:

What information that seems unimportant today may be useful in the future. Your records create a history of development gains or set backs and provide a single source of health and medical records and information that will be needed by teachers, therapists and doctors.

Health and medical records

Make lists of doctors, notes about appointments, medicines prescribed including side affects. The Utah Collaborative Medical Home project's website <http://medhomeportal.org> has extensive forms that will be helpful to maintain your records.

School records

As soon as your child begins receiving services either through the Baby Watch Early Intervention Program or the school system, records are critical. Keep notes from meetings with school staff and teachers, professional health care providers, developmental assessments, educational evaluations, and all individualized plans developed for your child. Remember that assessments and therapy notes from private therapists are also important.



Financial records

Financial records are critical. As soon as parents find out that their child has a disability, they should begin to organize. Start a program to organize and manage your new financial demands. This not only means managing of everyday money, but keeping very careful track of your medical bills and payments. There are a number of money management guides available in most retail stores that explain how to do this.

RESOURCES AND SUPPORTS

- Seek Information about financial assistance and service programs
- Use all resources

Seek information about financial assistance and service programs:

Seek information about any and all assistance programs. State agencies, like Medicaid, may be able to pay for medical services from the start. Early intervention programs work with children as young as a day old.

Use all resources:

Often, so much attention is focused on getting services for the child that service providers and medical offices may not mention available sources of financial aid.

- Ask questions
- Get information
- Become knowledgeable

- You might want to contact the Division of Services for People with Disabilities (DSPD). Your child may be eligible for DSPD services. Children with more extensive needs are prioritized to receive services more quickly.
- Many children with disabilities are eligible to receive Supplemental Security Income (SSI) benefits, based upon their disability.

- Women, Infants & Children Nutrition Services (WIC) provides nutrition education and nutritious foods to help keep pregnant women, new mothers, infants and preschool children healthy and strong through the WIC Program. This service will often be able to provide specialized formulas for children with feeding problems.
- Medicaid can make it possible for you to get the care that you need so that your child can get healthy – and stay healthy.

Notes:

GETTING OLDER AND MORE INDEPENDENT

These settings contain many opportunities for choice and decision-making.

- Ensure that your child has opportunities
- Teach your child
- Help your child develop self-determination and self-advocacy skills
- Work with school and other agencies

Ensure that your child has opportunities:

Ensure that your child has the opportunity to acquire skills now that will make him or her as independent as possible in the future. To live even somewhat independently requires that your child be able to dress, eat, and provide personal care for themselves. Ensure that your child has opportunities to develop social skills that can be used in a variety of settings (regular classroom settings and exposure to many different environments are useful).

Teach your child:

Let them be responsible for their personal needs. This includes experience with:



- Budgeting – opening checking and savings accounts,
- Management of Personal Assistants – recruiting PA's, developing job responsibilities and funding sources,
- Transportation – use of city bus and para-transit services

Help your child develop self-determination and self-advocacy skills:

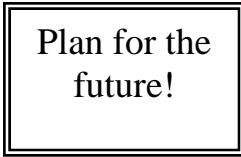
Teach your child to be responsible for his or her own personal needs (e.g., self-care, household chores). Provide opportunities for your child to spend time in community settings. These settings contain many opportunities for choice and decision-making.

Work with school and other agencies:

Work with the school and other agencies to ensure that transition planning for your son or daughter takes place and addresses training for future employment, coordination with adult service providers, investigating postsecondary education or training, and participation in community activities.

PLANNING FOR THE FUTURE

- Plan for when you can't be there
- Explore living options



Plan for when you are no longer able to care for your child:

Seek information from a reputable source to help with estate planning that will provide for your child's care and safeguard his or her eligibility for government benefits.

Explore living options:

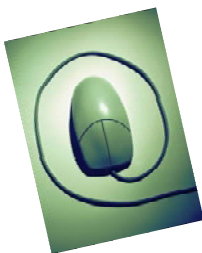
Explore different possibilities for living arrangements once your son or daughter is grown. Most communities offer services that range from minimum supports and supervision to twenty-four hour on-site supervision to hands-on care.

Notes:

ORGANIZATIONS AND AGENCIES

There are many organizations and agencies that can help you in a caregiving role. Use these resources, talk with people about your needs and feelings.

There is a list of local, state and national agencies in your packet.



- **Special Child: For Parents of Children with Disabilities**
www.specialchild.com
- **NICHCY, National Information Center for Children and Youth with Disabilities** www.kidsource.com/NICHCY
- **Utah Parent Center, Phone: 801-272-1051**
www.utahparentcenter.org The Utah Parent Center offers free training, information, referral and assistance to parents and professionals through the provision of information, referrals, individual assistance, workshops, presentations and displays

The Medical Home has extensive forms that will be helpful to maintain your records at www.medhomeportal.org

- Family Voices, is a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals.
- Contact Utah Family Voices at www.utahfamilyvoices.org or utahfamilyvoices@juno.com

Notes:

RESOURCES FOR CHILDREN WITH SPECIAL NEEDS

Utah Department of Health

- Children with Special Health Care Needs – For general information, call 584-8284 in the Salt Lake area or statewide toll free at 1-800-829-8200.
- Baby Watch Early Intervention (for children birth to three) - toll free 1-800-961-4226
- Child Development Clinic (for children birth to five) - 801-584-8510
- Assessing Behavior in Learning Environments (for school-age children) – 801-584-8552

Services, Equipment, Subsidies, Help, Etc.

- Access Utah Network provides information pertaining to disabilities (Services, supports, adaptive equipment—new/used—Library on ADA) 801-533-4636 or 1-800-333-8824
- DSPD—Division of Services for People with Disabilities Provides respite care, supplements daycare fees, links with other local supports. Call 801-538-4200

- SSI—Supplemental Security Income Stipend for children and adults with disabilities; must be disability and income eligible. Salt Lake City area 524-4115 National office locator service available at 1-800-772-1213 or TTY: 1-800-325-0778
- UCAT—Utah Center for Assistive Technology computer and assistive technology for people with disabilities at 801-887-9500 or 1-888-866-5550 (toll free within Utah only)
- Utah Independent Living Center assists people with disabilities in independent living (advocacy, support groups, recreational activities, funding sources for increased independence) 801-466-5565 or 1-800-355-2195 (toll free within Utah only)
- WIC (Nutrition Services for children birth to five) 801-942-5437 (WIC-KIDS) or toll free 1-877-942-5437

Early Intervention and Special Education Preschools/Schools

- Baby Watch Early Intervention 1-800-961-4226
- Call your local school district for information on:
 - Special Education Services
 - Special Education Preschool
- Head Start-call local program or www.acf.hhs.gov/programs/hsb/
- Carmen B. Pingree School for Children with Autism 801-581-0194 (Ask for Robin Gochnour) Provides early intervention services using Applied Behavioral Analysis techniques

Mental Health Services

- Call the Utah Division of Mental Health to find the Community Mental Health Center nearest to you: 801-538-4270
- The Children's Center 801-582-5534 (East Center – Salt Lake City) or 801-966-4251 (Kearns Center - Kearns)
- Mental health/behavior problem treatment for children ages 2 to 7 University of Utah Child & Adolescent Specialty Clinics 801-585-1212 (Dr. Judith Miller)

Support, Advocacy Groups, Etc.

- Autism Society of Utah 801-583-7049
- Autism Society of America 1-800-328-8476
- CHADD—Children and Adults with Attention Deficit Disorder 801-537-7878
- Child Care Connection 801-537-1004
- Disability Law Center 801-363-1347 or toll free 1-800-662-9080 (TTY: 801-924-3185)
- Easter Seals 801-486-3778
- Respite program –ask specifically for Family Friends—three-four hours/week by volunteers. Saturday evening drop-off for children, \$8.80/hr

- Family Support Center 801-487-7778 (Sugarhouse) or 801-255-6881 (Midvale)
- Crisis nursery, parent support groups throughout Utah
- Learning Disabilities Association of Utah 801-323-6320
- LINCS Parent Advocate 801-281-4425 or toll free 1-877-335-4627 Consult about your rights in IEPs; will attend IEPs and advocate for you if needed. Ask for Sherilin Rowley
- Parent-to-Parent 801-856-9795 or 1-800-468-1160 (toll free within Utah only)
- Utah Parent Center 801-272-1051 or toll free 1-800-468-1160 Information, workshops and consultation for your child's IEP Workshops—stress management, bringing your child through transition phases, etc. Parent Consultants—parents who have “been there.”

Therapy Services – physical therapy, occupational therapy, and speech therapy

- Primary Children's Medical Center 801-588-3950 (Other offices: North (in Bountiful): 801-292-8665; West (in Taylorsville): 801-840-4360 South (in Sandy): 801-571-1223; Ogden: 801-395-2634)
- Scottish Rite Children's Learning Center 801-486-0579 (Salt Lake City) or 801-627-8878 (Ogden)
- University of Utah Communication Disorders Clinic 801-581-3506
- UFIT – U of U physical activity program for special needs kids 801-587-9713